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An educational program in breast cancer screening for first-degree relatives of breast cancer patients

Sharp, Penny Cunningham, Ed.D.

The University of North Carolina at Greensboro, 1990

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AN EDUCATIONAL PROGRAM IN BREAST CANCER SCREENING FOR FIRST-DEGREE RELATIVES OF BREAST CANCER PATIENTS

by

Penny Cunningham Sharp

A Dissertation Submitted to
the Faculty of the Graduate School at
The University of North Carolina at Greensboro
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

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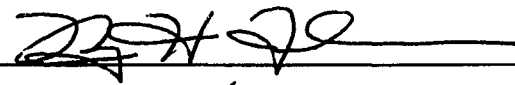
Approved by

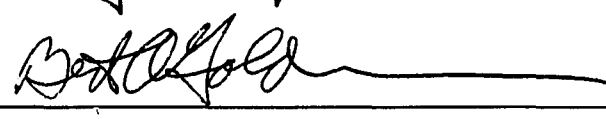
Dissertation Adviser

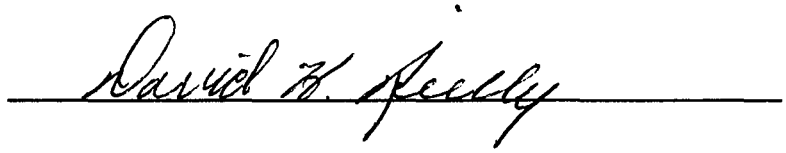
APPROVAL PAGE

This dissertation has been approved by the following committee of the Faculty of the Graduate School at the University of North Carolina at Greensboro.

Dissertation Advisor 

Committee Members 





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SHARP, PENNY CUNNINGHAM, Ed.D. An Educational Program in Breast Cancer Screening for First-degree Relatives of Breast Cancer Patients. (1990) Directed by Dr. Charles M. Achilles. 75 pp.

The purpose of this study was to evaluate an educational program for asymptomatic first-degree female, adult relatives of breast cancer patients designed to increase their participation in breast cancer screening. Two hundred patients were enrolled in the study when they came for out-patient breast cancer treatment at Bowman Gray School of Medicine. Each participating patient supplied personal information on either a sister, daughter or mother which enabled contact through mail and telephone with the relative. The relatives were randomly assigned to either experimental or control group with 191 completing the study. A posttest only research design was employed. Each member of the experimental group received a packet of mailed information and a nurse's phone call, both encouraging screening, followed by a posttest questionnaire three months later. Breast self-exam (BSE), clinical breast exam (CBE), and mammography were explained and participation in screening encouraged. Women in the control group were given the posttest questionnaire 3 months after their relatives were enrolled in the project, followed by the intervention. The efficacy of the Health Belief Model (HBM) to predict screening participation was also assessed.

The study participants consisted primarily of white, married, middle-class women with a mean educational level of 12.5 years. Most of the patients discovered their own breast lumps; 42% during BSE, 39% by accident. Almost half of the relatives do not have CBEs as recommended by the American Cancer Society (ACS), and over 60% do not have mammograms as recommended.

Difference of proportions test (chi-square) revealed that women in the experimental group were more likely to practice BSE ($p \leq .05$), but were not more likely to participate in CBE or mammography. Women did report changes in screening behaviors as a result of the program (26 for BSE, 13 for CBE, and 17 for mammogram). Knowledge of breast cancer was significantly higher for women in the experimental group ($p \leq .05$). The greatest predictor of breast screening behaviors was the HBM, followed by subjects' income.

An educational program can increase participation in breast self-exam and knowledge of breast cancer.

ACKNOWLEDGEMENTS

Although their names will remain unknown in order to provide the anonymity which they were promised, I must first acknowledge the breast cancer patients and their mothers, sisters, and daughters who were willing to participate in this study. Without their involvement, this project would not have been possible.

I wish to thank Dr. Charles Achilles, for his willingness to serve as dissertation advisor, Dr. David Reilly who provided encouragement for pursuing this topic, and to Drs. Rex Culp, Roy Forbes, and Bert Goldman who were willing to serve as committee members. Your expertise and helpfulness are greatly appreciated.

In addition to the UNC-G committee, I was fortunate to have a committee from the Department of Family & Community Medicine (Bowman Gray School of Medicine, Wake Forest University). Thanks to Drs. Larry Camp, Mark Dignan, and Bob Michielutte.

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Most of all, thank you to Bob, and our sons, Trey, Tom and Jim - for everything.

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CHAPTER I

INTRODUCTION

One of the major economic problems in the United States concerns the rising cost of medical care. As costs rise, it becomes apparent that the move toward cost containment will grow and that mass screening programs designed to screen generally healthy people will be curtailed. As a result, it has been recommended that screening activities be focused toward high risk groups in order to show more cost benefits (Jensen, 1982). Within this context, health education programs designed specifically for a high risk population should be implemented and evaluated in terms of both effectiveness and cost. Some diseases or conditions have both well-defined high risk groups and good prognoses if detected early and treated properly. One such disease is breast cancer (Wright, 1986).

Significance

One of the leading causes of morbidity and mortality among American women is breast cancer. It is the most commonly occurring cancer in women and is the leading cause of cancer death among women. An estimated one out of ten women in this country will develop breast cancer and in 1989, approximately 142,900 new cases will be diagnosed and 43,300 women will die of the disease (American Cancer Society or ACS, 1989; Carter, Jones, Schatzkin & Brinton, 1989).

While many risk factors for cancer of the breast have been identified, a positive family history is one of the strongest. The risk for a woman with a positive family history of premenopausally diagnosed breast cancer in a first-degree relative (sister, mother or daughter) is two to three times that of a woman of the same age in the general population with no family history of breast cancer (Helmrich, et al., 1983; Kelsey, 1979; Kelsey, Hildreth & Thompson, 1983; McLellan, 1988). The risk is greater if the first-degree relative had bilateral breast cancer (Bachman, 1988).

Although numerous factors influence survival rate after diagnosis, tumor stage at diagnosis is currently the most important documented prognostic factor (Hayward, Shapiro, Freeman, & Corey, 1988; Silvestrini, Diadone, DiFronzo, Morabito, Valagussa & Bonadonna, 1986). Therefore, early detection by aggressive screening has been recommended using breast self-examination (BSE), clinical breast examination (CBE) and mammography.

There is evidence that women with family histories of breast cancer neither consider themselves to have an increased risk nor are they more likely to participate in screening than are women without a positive family history (Taylor and Billingham, 1988). There is also evidence that familial breast cancer patients respond more readily to treatment than do other breast cancer patients (Lynch and Lynch, 1981), thus providing these women with better prognoses with early detection.

This project addressed the issue of breast cancer screening for a group of women who are generally considered to be at high risk for the disease, who have a good prognosis for cure if the disease is detected at an early stage, but who are unlikely currently to be participating in screening activities. If successful, this project would provide a program which may increase the participation of high risk women in breast cancer screening activities and, therefore, theoretically would reduce the number of women who die from this disease.

Conceptual Basis

The conceptual basis for this study was:

1. Epidemiology of breast cancer
2. Breast cancer screening activities
3. Program development, implementation, and evaluation.

Purpose

The purpose of this study was to design, implement and evaluate an educational program providing information to encourage participation in breast cancer screening for asymptomatic first-degree female, adult relatives of breast cancer patients.

The Problem

The problem was to determine if a program specifically designed to target women at high risk for breast cancer will increase their participation in screening activities when compared to a control group.

Hypotheses

The following hypotheses were tested. Differences were considered significant if they reached or exceeded the $p \leq .05$ level of significance.

H_1: There would be significant differences between the experimental group and the control group with participation in breast self-examination, clinical breast examination, or mammography activities.

H_2: There would be significant differences between the experimental group and the control group in awareness and knowledge of breast cancer and breast cancer screening activities.

Definitions

For clarification, the following terms are defined as follows:

1. Breast self-examination (BSE): an examination of all breast tissue as a woman examines her own breasts in a mirror and through palpation.
2. Clinical breast examination (CBE): an examination of the breasts by a health professional, usually a physician or physician assistant.
3. First-degree adult female relative: mother, sister or daughter 18 years of age or older.
4. Mammography or mammogram: an x-ray examination of the breasts.

Delimitations

This study was delimited by two important factors.

1. The study only included first-degree adult, female relatives of breast cancer patients in either the Radiation Therapy Clinic or the

Hematology/Oncology Clinic of the Bowman Gray School of Medicine of Wake Forest University. The relatives had to live within the catchment area of the Bowman Gray School of Medicine of Wake Forest University which includes parts of North and South Carolina, Virginia, Tennessee, and Georgia.

2. Data were collected from the breast cancer patients through face-to-face interviews and their relatives through telephone interviews. Relatives who could not be reached by telephone were not included in the study.

Limitations

This study was limited by three factors.

1. The willingness of patients to provide the name, address and telephone number of a relative who met the study criteria.
2. The accuracy of the self-reported data concerning breast cancer screening activities.
3. The relatively short length of time (three months) between intervention and posttest interview.

CHAPTER II

REVIEW OF THE LITERATURE

Epidemiology of Breast Cancer

One out of every ten women in the United States is likely to develop breast cancer. It is one of the leading causes of morbidity and mortality and is the leading cause of cancer death among American women (ACS, 1980 & 1989; Carter, 1989). In 1989, approximately 43,300 women died of this disease (ACS, 1989). In addition, breast cancer alone accounts for nearly 26% of all years of potential life lost before the age of 65 due to cancer (Mortality and Morbidity Weekly Report, 1987). The incidence of the disease is increasing progressively throughout the world and, while in the United States the incidence is one of the highest, it is still increasing, especially in women under the age of 40 (Humphrey & Ballard, 1989). North Carolina ranks 26th in the United States in age-adjusted mortality rates from breast cancer in women, with 32 per 100,000 (Mortality and Morbidity Weekly Report, 1989).

While there are well established risk factors for breast cancer, approximately 75% of breast cancers occur in women with no known risks (Seidman, Stellman & Mushinski, 1982; Strax, 1987). It is, therefore, important to recognize that all women have the risk for developing this disease even though some are much more

vulnerable. There is clear evidence that both genetics and lifestyle choices may increase a woman's risk.

Extensive study of the disease has resulted in labeling several variables as risk factors. Incidence of breast cancer increases with age, so that risk of the disease is six times higher at age 70 than at age 40 (Strax, 1977; Dupont & Page, 1985). Age at the time of certain milestones in a woman's life also appears to alter her risk. A relatively recent trend toward delayed childbirth increases risk (White, 1987). Age greater than 30 years at first birth, or never having had a child, have both been associated with increased breast cancer risk (Lynch & Lynch, 1981; Dupont & Page, 1987; Blot, 1980; White, 1987; Schatzkin, 1987; Brinton, Hoover & Fraumeni, 1983; Carter, 1989; Helmrich, 1983). Early age at onset of menstruation or late natural menopause are also well documented risks (Humphrey, 1989; Lynch, 1981).

Exposure to radiation (Shore, Hildreth, Woodard, et al., 1986; Boice & Monson, 1977), personal history of endometrial or ovarian cancer (Humphrey, 1989), higher socioeconomic or educational status and Jewish heritage (Carter, 1989; Helmrich, 1983) are all associated with higher risk of the disease.

Factors related to diet which are associated with greater risk include even moderate alcohol consumption (Schatzkin, 1987; Willett, Stampfer, Colditz, Rosner, Hennekens & Speizer, 1987; O'Connell, Hulka, Chambless, Wilkinson & Deubner, 1987) and obesity and/or high fat in the diet (Lubin, Ruder, Wax, &

Modan, 1985; Schatzkin, 1987; Willett, Stampfer, Colditz, Rosner, Hennekens & Speizer, 1987; Lubin, Wax & Modan, 1986).

The greatest known risk factor for breast cancer is a positive personal or family history of the disease (Humphrey, 1989; Dupont, 1987; Vakil, Morgan & Elinson, 1981; Carter, 1989; Anderson, 1972; Helmrich, 1983; Brinton, Hoover & Fraumeni, 1983; Lynch, 1981). The risk is higher for relatives with premenopausal diagnoses or if the disease was bilateral. If the disease is both premenopausal and bilateral, the relative risk is nine times that of women with negative family histories (Anderson, 1972; Leis, Greene, & Hilfer, 1986; Lynch, 1981).

Although numerous factors influence survival rate after diagnosis, tumor stage at diagnosis is currently the most important documented prognostic factor (Harward, 1988; Silvestrini, 1986). Therefore, early detection by aggressive screening has been recommended, especially for women known to be at high risk (Wright, 1986).

Screening is a procedure to detect undiagnosed disease in an asymptomatic individual (Strax, 1977). Aggressive screening programs reduce the probability of death from the disease by approximately 10 out of 10,000 (Eddy, 1989). Studies have shown that screening has a positive effect on reducing mortality (Shapiro, Venet, Strax, Venet & Roeser, 1982; Shapiro, 1977; United States Preventive Services Task Force or USPSTF, 1987). The methods of screening which are currently used for breast cancer are breast self- examination (BSE), clinical breast examination (CBE), and mammography.

Breast Self-Examination (BSE)

Most breast cancers are found by women themselves and for this reason breast self-examination has been recommended as a low-cost, low-risk, self-screening method for detecting breast cancer at an early stage (Humphrey, 1989). The goal in BSE is to find breast lumps at their smallest palpable size before the disease has progressed and when chances of cure are the highest. Despite published reports that BSE can lead to earlier diagnosis (Mant, Vessey, Neil, McPherson, Jones, 1987), whether or not this alone leads to improved mortality from breast cancer is unclear (United Kingdom Trial of Early Detection of Breast Cancer Group, or UK Trial, 1981 & 1988).

Many researchers have attempted to evaluate the effectiveness of BSE with varying success. Two studies which have received a great deal of attention as controlled studies on the effectiveness of BSE are from the United Kingdom and the Soviet Union (UK Trial, 1981 & 1988; Semiglazov & Moiseenko, 1987). The Soviet Union study has enrolled 62,252 women into an experimental group (who receive instruction in BSE) and a control group to test the effectiveness of this screening modality on breast cancer mortality. Data should be available in 1990. In the UK study, 45,841 women were offered annual screening with clinical examination and mammography every other year; 63,636 women were offered BSE instruction and a self-referral clinic, and over 120,000 women were studied as a control group. After seven years, no difference in mortality has been observed between the group which was offered BSE instruction and the control group.

Cole and Austin (1981), in an evaluation of the data from BSE effectiveness studies, concluded that the benefits of BSE may be small for women who use clinical examination and mammography as recommended. However, it may be an important modality for early detection of breast cancer in women who do not use these services.

Although most primary care physicians recommend BSE to their female patients (ACS, 1985), and 95% of the women in the United States know about BSE, only 27% report regular monthly BSE. Even among women with previously diagnosed breast cancer, only 43% practice BSE on a monthly basis (Holleb, 1979; McLellan, 1988). One reason for noncompliance with BSE may be the psychological cost to the woman when she has to face the issue each month that she is at risk for breast cancer (O'Malley & Fletcher, 1987). A second issue which has not been fully explored is the economic cost for evaluation of noncancerous breast lumps and the cost of teaching BSE in terms of personnel and time. The cost-effectiveness of BSE has not been clearly established.

Lack of evidence supporting the use of BSE has lead the U.S. Preventive Services Task Force (USPSTF) to make no recommendations about the inclusion or exclusion of teaching BSE as a part of periodic health examinations (USPSTF, 1987). The World Health Organization's (1984) statement on BSE is as follows:

> There is insufficient evidence that BSE as applied to date is effective in reducing mortality from breast cancer. Therefore, BSE screening programmes are not at present recommended as public health policy,

> although there is equally insufficient evidence to change them where they already exist (p 867).

However, the lack of definitive evidence that BSE is not effective, together with the potential benefit for women who are unlikely to routinely use the other screening methods (eg., due to cost, etc.) suggest that promotion of BSE can be a valuable component in a comprehensive educational program. The American Cancer Society recommends monthly BSE for all women over the age of 20 (ACS, 1980).

Clinical Breast Examination

Clinical breast examination (CBE) alone has not been evaluated in a randomized controlled trial. However, descriptive studies support its effectiveness in detecting early stages of cancer and improving survival rates (Baker, 1982; Gilbertsen & Kjelsberg, 1971; Senie, Rosen, Lesser & Kinne, 1981). The Health Insurance Plan of Greater New York (HIP) utilized a randomized trial designed to evaluate the effectiveness of mammography and clinical examination to detect early breast cancer and reduce breast cancer mortality (Shapiro, 1977; Shwartz, 1978). In this study, 45% of all breast cancers were detected by CBE alone, 33% by mammography, and 33% by both modalities. Further analyses revealed that a major portion of the combined 33% was due to the physical exam alone. The relative contribution of CBE and mammography varied with the patient's age. In women less than 50 years old, 61% of the tumors would have been missed with mammography alone and 19% would have been missed with CBE alone. In

women older than 50, mammography and CBE contributed equally to cancer detection. Similarly, in the Breast Cancer Detection Demonstration Project (BCDDP), 9% of all breast cancers missed by mammography were found on clinical examination (Baker, 1982). However, it is important to note that CBE is limited in that tumors must be of a certain size and consistency to be palpable. Most lumps less than 1 cm in size will be missed on clinical examination (Fletcher, O'Malley & Bunce, 1985; Hicks, Davis, Layton, Present, 1979). The specificity of clinical breast examination in the BCDDP was 95% and the positive predictive value was 49%.

Since evidence supports the effectiveness of CBE, it has been recommended annually for all women over the age of 40 and more frequently for women with histories of breast cancer, with histologically proven cystic breast disease, and with a family history of breast disease in a first-degree relative (ACS, 1980; Fletcher & O'Malley, 1986; Strauss, Solomon, Costanza, Worden & Foster, 1987; USPSTF, 1987). The American Cancer Society recommends clinical examinations for women between the ages of 20 and 40 every 3 years (ACS, 1980). For women with family histories of premenopausally diagnosed breast cancer in a first-degree relative, the U. S. Preventive Services Task Force recommends CBE for women 19 to 39 years of age.

Mammography

Several studies evaluating mammography as a screening tool for asymptomatic women have shown that it can reduce mortality from breast cancer. At 14 years

of follow-up, the Health Insurance Plan (HIP) study showed a 20% reduction in mortality among the study group (31,000 women) as compared to the similarly-sized control group (Feig, 1988). Of the breast cancers detected in the screened women, one-third were detected by mammography only and of those, 79% had negative axillary nodes at surgery. In the control group, only 48% had negative axillary nodes at the time of surgery. Subsequent research has supported the results of the HIP study (Stevens, Moolgvkar, & Lee, 1982; Tabor & Dean, 1987).

Based on the evidence that early detection of breast cancer is possible, annual screening with mammography and clinical examinations are recommended for women greater than 50 years old. The ACS recommends a baseline screening mammogram between the ages of 35 and 40 and biennial mammography after age 40 (Humphrey, 1989). The U. S. Preventive Services Task Force recommends mammography for women, 19-39 years of age, who have a first-degree relative with premenopausally diagnosed breast cancer. It recommends mammograms every year or two for women beginning at age 50 until age 75, with annual CBEs starting at age 40 (USPSTF, 1987).

Summary

Because tumor stage at diagnosis is the most important documented prognostic factor and all three modalities for early detection of breast tumors have been shown to be effective, this project encouraged women to participate in BSE, CBE and mammography.

Self-Report of Health Behaviors

New studies on the validity of self-reported health behaviors have revealed encouraging information. While the results of various inquiries into self-report have reported varying degrees of accuracy, there appears to be an agreement that self-report is a valid manner of collecting information (Strecher, Becker, Clark & Prasada-Rao, 1989; Bush, Miller, Golden & Hale, 1989; Cleary & Jette, 1984; Sawyer, Earp, Fletcher, Daye & Wynn, 1989; Baranowski, 1985; Paganini-Hill & Ross, 1982; Harlow & Linet, 1989; Bean, Leeper, Wallace, Sherman & Jagger, 1989). This project relied on the accuracy of self-reported screening behaviors of the participants as the only means of data collection.

Educational Intervention

There have been many interventions designed to persuade women to participate in screening for breast cancer, especially BSE (Baker, 1982; Beaman, 1988; Grady, Kegeles, Lund, Wolk & Farber, 1983) and some have been more effective than others. However, Gold (1964) found that relatives of breast cancer patients avoided recommended examinations and screening, intensely fearful that a malignant tumor would be found. Another study revealed that even after special education about the value of BSE, women with positive family histories for breast cancer were less likely to perform monthly BSE than other women in the study (Worden, Costanza, Foster, Lang & Tidd, 1983). In contrast to these studies, however, Strauss, et al. (1987) found that women with personal histories of breast cancer were more likely to practice BSE regularly and that they perceived cancer

to be less threatening than did a control group of non-cancer patients. Bennett, et al. (1983) found that women with maternal histories of breast cancer were more likely to perform monthly BSE.

This intervention was based on the Health Belief Model (HBM) which has been used as a theoretical model for other public health education programs specifically designed to encourage participation in BSE (Champion, 1985 & 1988; Hallal, 1982; McLellan, 1988). The HBM explains a person's likelihood of taking preventive action in terms of the perceived threat of the disease weighed against the perceived benefits and barriers to taking the action and the perceived ability of the individual to take the desired action. Theoretically, intervention at any point in the model may enhance the probability of the desired action (Rosenstock, 1974; Rosenstock, Strecher & Becker, 1988).

While many different approaches have been used as means for increasing participation in breast cancer screening, this approach was unique in that: (1) it focused on a specific high risk population [first-degree relatives of breast cancer patients] and, (2) it addressed cost as a factor by using nurses rather than physicians.

The intervention was designed to encourage first-degree adult female relatives of breast cancer patients to participate in screening programs for breast cancer. It was both a time and cost-effective program in that the intervention used a research assistant and a nurse, rather than physicians, and materials were mailed to the participants. Contacts as part of the intervention and for posttest

interviews were by telephone. Similar programs (Beckie, 1989; Iams, Johnson, O'Shaughnessy & West, 1987) have employed the use of telephone calls by nurses as part of the intervention quite successfully and cost-effectively (Bertera & Bertera, 1981), although difficulty in reaching the women by telephone has been noted as a constraint.

CHAPTER III

METHODOLOGY

Introduction

The intervention was intended to encourage first-degree female relatives of breast cancer patients to participate in screening programs for breast cancer. The program was designed to be both time and cost-effective. Rather than physicians, the intervention utilized a research assistant and a nurse to contact patients, and materials were mailed to participants. Contact as part of the intervention and for posttest interviews was by telephone.

Research Design

The research design was a posttest only design. This approach allowed for randomization without the possible biases which might have been introduced by pretesting as shown in Figure 1.

Figure 1. Posttest only research design

Groups				
Experimental	R	X	O	
Control	R		O	X

'R' = random assignment into either the experimental or control group

'X' = intervention

'O' = posttest interview

Since the most adequate all-purpose assurance of lack of initial biases is randomization, this design is particularly useful in educational research where pretests are impractical or likely to introduce biases (Campbell & Stanley, 1963).

Subjects

Subjects were first-degree female relatives of breast cancer patients. They included adult mothers, sisters, and daughters of patients who received medical care for breast cancer at the Bowman Gray School of Medicine. The initial contacts were consecutive adult patients in the Radiation Therapy Unit and the Hematology/Oncology Clinic of the Bowman Gray School of Medicine of Wake Forest University. During February and March, 1990, each breast cancer patient was asked to participate in the study. Those who agreed signed an informed consent form, and completed a short questionnaire (see Appendix A). The patients who agreed were asked to supply the name, address and telephone number of a first-degree female relative. Only adult relatives who lived in the catchment area of the medical school were eligible. The catchment area included parts of Georgia, North and South Carolina, Tennessee, and Virginia. Those patients unable to supply the name of a first-degree relative who lived within the study region were excluded from the study. The relatives were randomly assigned by computer-generated random number assignment to either intervention or control group. It was necessary to interview 301 breast cancer patients for the study in order to accrue the 200 patients required to complete the study. Eighty-eight patients were ineligible because they did not have a relative who qualified

for the study. Only 13 patients refused to participate; 8 stated that they did not feel well enough to be interviewed, and 5 were not interested.

Figure 2 presents a flow chart showing the plans for data collection from the experimental and control groups.

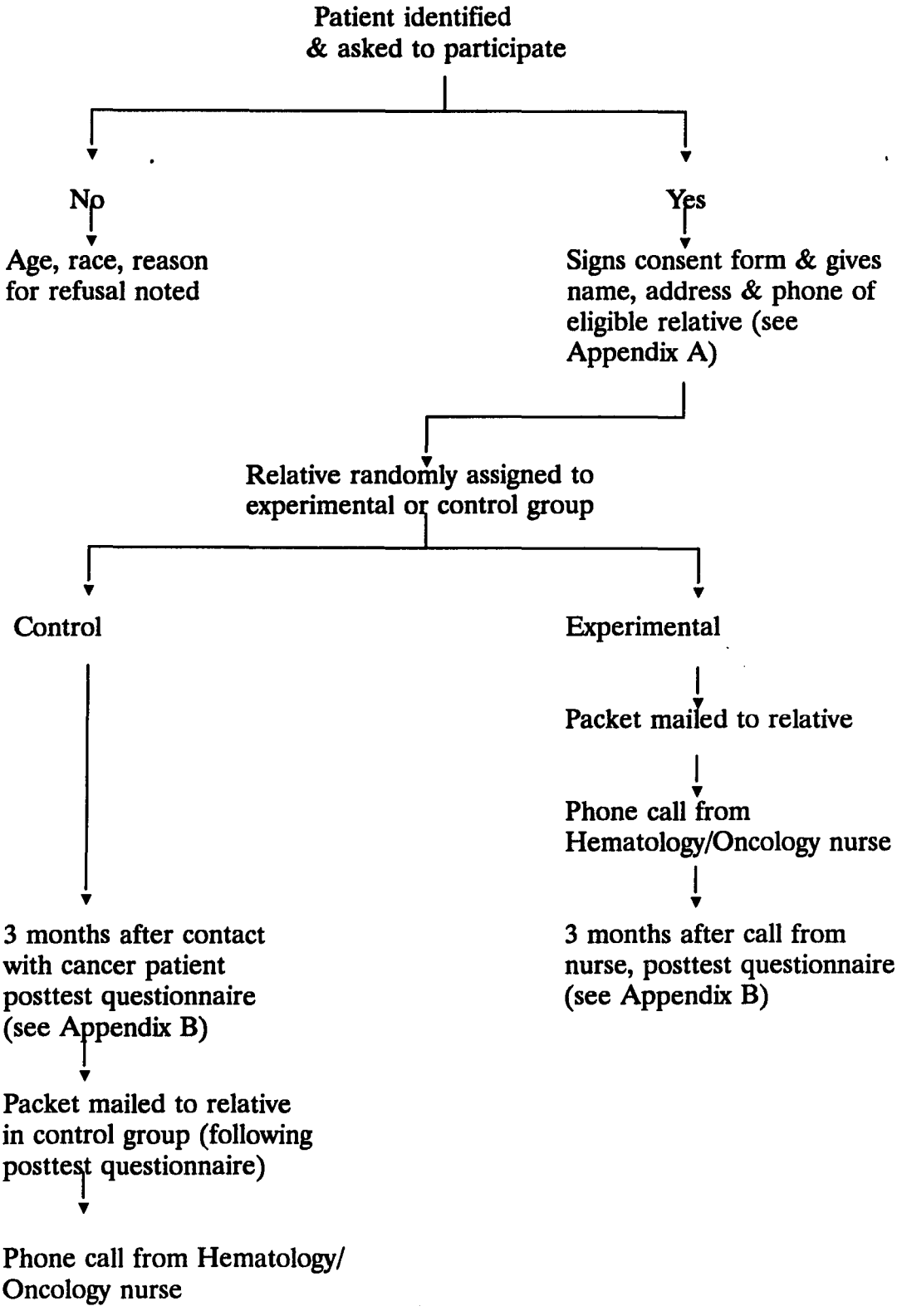
Intervention

Available printed materials were reviewed by the principal investigator and, with the exception of a specific brochure designed to address the needs of breast cancer patients' relatives, no new materials were needed. One brochure developed specifically for this project highlighted the need for breast cancer screening activities by relatives of breast cancer patients. With the completion of this brochure, a packet of educational materials concerning breast cancer was assembled and mailed to each relative in the intervention group. The packet included:

1. A letter explaining why the materials were being sent.
2. National Cancer Institute pamphlet, "Breast Exams: What You Should Know" (NIH Publication No. 89-2000), which covers in detail all three methods of breast examinations.
3. Pamphlet specifically designed by the principal investigator for relatives of breast cancer patients (Appendix C).

In addition to the packet of materials, each woman in the experimental group was phoned by a Hematology/Oncology nurse who: (1) explained the project and

Figure 2. Flow chart of experimental design for the breast cancer education program for first-degree relatives, 1990.



answered any questions about the project; (2) encouraged participation in breast cancer screening; (3) answered any questions which the woman had about breast cancer.

Data Collection

The experimental group participants received the packet in the mail, followed by a phone call from the project nurse, and a second phone call from either the principal investigator or a research assistant three months after the nurse's call. The three month waiting period allowed time for the participant to: (1) make an appointment for a clinical breast examination and/or a mammogram; (2) make arrangements to learn breast self-examination; or (3) continue with the screening program that the participant was already practicing. The principal investigator or the research assistant explained the purpose of the project and encouraged the participants to participate in the evaluation. If they agreed, the questionnaire was administered over the phone.

Data were coded and ten percent were recoded to assure accuracy. No mistakes were detected; therefore, no additional double-coding was required. All data were encoded and verified before analysis began.

Measurement

Demographic data were collected from both the patient and the participating relative in order to compare the study population with characteristics previously found to be associated with breast cancer. These data included age, race, marital

status, total household income the previous year, and education (last grade of school completed).

Patients were questioned as to the history of their own breast cancer, including: (1) diagnosis before, during or after menopause; (2) how the breast cancer was discovered; (3) whether or not the patient had discussed her disease with the relative she named; (4) whether or not she thought that her relative participated in breast cancer screening; and, (5) family history of breast cancer. Relatives were asked similar questions concerning discussion of the patient's disease and whether or not the patient encouraged screening.

Relatives in the experimental and control groups also were asked specific questions concerning participation in breast self-exam (BSE), clinical breast exam (CBE), and mammography in the past three months. Additional data were collected on each component of screening. Questions were asked concerning BSE class attendance, interest in a BSE class and whether or not the women felt that they were doing BSE correctly. Additional information on CBE included whether or not the relative ever had a CBE exam, whether the CBEs were within the schedule recommended by the American Cancer Society (ACS), interest in having another CBE in the future, and perceived difficulty in making and keeping an appointment for a CBE in the future. Similar questions were asked in regard to mammography.

Relatives in the experimental group were asked additional questions concerning the impact of the program. Separate data were collected for each

screening technique. The women were asked two specific questions for each technique: (1) Have you done anything differently about (BSE, CBE, or mammography) as a result of either the packet of information you received from us or the nurse's phone call? (2) If yes, what? and If no, why not?

Analysis Plan

In order to examine the efficacy of the Health Belief Model (HBM) in predicting screening behaviors in this project, several questions were included in the data collection. In addition to the questions which focused on intended behaviors and barriers to screening, relatives were asked how concerned they were about breast cancer (perceived seriousness), how likely they thought it was that they might get breast cancer (perceived susceptibility) on Likert-type scales of 1 to 5, and what percent of breast cancer can be cured if found early and treated correctly (perceived benefit of early diagnosis and treatment). A HBM score was computed by adding points for positive behaviors or perceptions, and subtracting for negative behaviors or perceptions. The scores ranged from -7 to +7.

Scores were constructed in order to test the second hypothesis concerning differences in awareness and knowledge between experimental and control groups. An awareness score was calculated by adding responses to questions on BSE (interest in attending a class in BSE), CBE (interest in having a future CBE), mammogram (interest in having a mammogram in the future), and concern about breast cancer. Response 3 (uncertain) was scored as zero for all questions and the total score was divided by 4 (total number of questions in the scale), for a

score which ranged from 1 to 5, with 5 indicating a high degree of awareness of breast cancer and need for screening. A knowledge score was calculated from responses to 2 questions on BSE (attendance in a BSE class and whether or not the woman felt she performed BSE correctly, both dichotomous variables), and the general question pertaining to percentage of breast cancer that can be cured. The responses to the general question were dichotomized at $\leq$ 84% (recoded as incorrect) and $\geq$ 85% (recoded as correct, since the generally accepted correct answer to the question is 90%). Scores ranged from 0-3, with 3 indicating higher degree of knowledge.

Statistical analysis employed the difference of proportions test (chi-square) and the t-test. The basic test employed was the difference of proportions test between the experimental and control groups for the proportion of women who engage in breast cancer screening.

In order to determine if there were any significant ($p \leq .05$) correlations between demographics, knowledge, awareness, the HBM, and screening behaviors, Pearson product-moment correlations were used.

CHAPTER IV

RESULTS

The results of the study are organized into two sections for presentation. The first section includes descriptive statistics, the second presents the results of the tests of the hypotheses.

Demographics

Demographic descriptors on patients and participating relatives are presented in Table 1. Frequencies and percentage distributions are shown for age (grouped), last year of school completed, marital status, race, total family income the previous year (1988-1989), time of diagnosis, how breast cancer was discovered, and if the patient discussed her breast cancer with the relative she named.

The participants consisted primarily of white, married, middle-class women who had a mean education of 12 years. The majority of the patients had discovered their own breast lumps, with about even numbers finding it during breast self-exam (BSE) and by accident. Almost 19% of the women who discovered their own breast lumps did so because of another symptom, such as pain or a rash. About 25% of the cancers were discovered by either clinical breast exam (CBE) or mammography, while 1.5% were discovered by either a husband or lover. There was no clear distinction as to the time of diagnosis in

Table 1. Characteristics of study participants, in breast cancer education program for first-degree relatives, 1990.

Variable	Patients		Relatives	
	Number	Percent	Number	Percent
Age				
≤ 39 years	23	11.5	72	36.0
40-49 years	47	23.5	41	20.5
50-59 years	60	30.0	27	13.5
60-69 years	40	20.0	32	16.0
≥ 70 years	30	15.0	18	9.0
Unknown	--	----	10*	5.0
Total	200	100	200	100
Education				
≤ 8th grade	31	15.5	16	8.0
9-11th grades	19	9.5	23	11.5
High School grad	85	42.5	71	35.5
Some college/grad	48	24.0	77	38.5
Post graduate	16	8.0	4	2.0
Unknown	1	.5	9*	4.5
Total	200	100	200	100

Table 1. (Continued)

Variable	Patients		Relatives	
	Number	Percent	Number	Percent
Marital Status				
Married	135	67.5	124	62.0
Single	9	4.5	18	9.0
Divorced	16	8.0	19	9.5
Widowed	36	18.0	25	12.5
Separated	4	2.0	5	2.5
Unknown	--	----	9*	4.5
Total	200	100	200	100
Family Income				
≤ $14,999	62	31.0	43	21.5
$15,000-24,999	38	19.0	43	21.5
$25,000-34,999	18	9.0	31	15.5
≥ $35,000	70	35.0	67	33.5
Unknown	12	6.0	16*	8.0
Total	200	100	200	100
Race				
Black	16	8.0	NA	NA
White	184	92.0		
Total	200	100		

Table 1. (Continued)

Variable	Patients		Relatives	
	Number	Percent	Number	Percent
Disease Related Variables				
Discussed Own Breast Cancer With Relative				
Yes	190	95.0	167	83.5
No	10	5.0	23	11.5
Unknown	--	----	10*	5.0
Total	200	100	200	100
Time of Diagnosis				
Before menopause	79	39.5	NA	NA
During menopause	15	7.5		
After menopause	76	38.0		
Post hysterectomy	28	14.0		
Unknown	2	1.0		
Total		200		
How Breast Cancer Was Discovered				
Self	143	71.5	NA	NA
Accident	(56)	(39.2)**		
BSE	(60)	(42.0)**		
Other Symptom	(27)	(18.9)**		
Clinical Exam	17	8.5		

Table 1. (Continued)

Variable	Patients		Relative	
	Number	Percent	Number	Percent
Mammogram	34	17.0	NA	NA
Husband/Lover	3	1.5		
Other	1	.5		
Unknown	2	1.0		
Total	200	100		

* - These numbers include those women who declined to participate in the study.

** - These numbers and percentages are for women who discovered the disease themselves.

relationship to menopause, with equal numbers of diagnosis before and after menopause. Over eighty percent of the patients and relatives agreed that they had discussed the disease among themselves. In addition, the patients' years of survival since diagnosis ranged from 0 (newly diagnosed) to 26 years, with a mean of 4.7 years, and S.D. of 5.34 years.

Seventy percent of the relatives were practicing BSE; almost half were having clinical exams as recommended by the ACS, but only one-third were following the ACS recommendations for mammograms, as shown in Table 2.

Table 2. Overall participation in screening by participants, 1990 study of breast cancer education for first-degree relatives.

	Did you participate in the following activities?			
	Yes		No	
	Number	Percent*	Number	Percent*
BSE	141	70.5	49	24.5
CBE	99	49.5	92	49.5
Mammogram	68	34.0	123	61.5

* Percentages do not total 100 due to missing information

Tests of the Hypotheses

Two hypotheses were tested at the $p \leq .05$ level of significance:

H_1: There would be significant differences between the experimental group and the control group with participation in breast self-examination, clinical breast examination or mammography.

H_2: There would be significant differences between the experimental group and the control group in awareness and knowledge of breast cancer screening.

The first hypothesis was tested by examining self-reported answers to screening questions. The relatives were asked if they had done breast self-exam

(BSE) had a clinical breast exam, or had a mammogram in the last three months. If they had not had a clinical breast exam (CBE) or a mammogram within the past three months, they were asked if they had ever had either and, if so, how long ago. The answers were scored as having had a clinical exam and/or a mammogram within the time schedule recommended by the American Cancer Society. Comparisons of proportions of women in the experimental and control groups who participated in screening were made using chi-square analysis with the criterion for statistical significance at $p \leq .05$.

The results of the test of the first hypothesis are shown in Table 3.

Relatives in the experimental group were also asked whether anything had changed as a result of the program. Twenty-six women reported differences in

Table 3. Overall participation in breast cancer screening by group, 1990 study of breast cancer education for first-degree relatives.

Variable	Experimental	Control	x^2	p
BSE	79 (56.03%)	62 (43.97%)	7.04	.008*
CBE	50 (50.50%)	49 (49.49%)	.00	.940
Mammogram	31 (45.59%)	37 (54.41%)	.49	.483

* Significant at the $p \leq .05$ level

breast self-exam, 13 reported differences in clinical exam, and 17 reported differences in mammogram. The 56 women who reported changes were then asked an open-ended question as to what changes had occurred. The responses are grouped in Table 4.

The second hypothesis was tested by comparing knowledge and awareness scores about breast cancer and breast cancer screening for experimental and control group participants, using Student's t-test with the criterion for significance $p \leq .05$. Results of t-test are shown in Table 5.

The efficacy of the Health Belief Model for predicting screening behavior in this population was examined. The HBM score which was computed by adding positive responses to questions concerning screening perceptions and intentions, and by subtracting responses for negative perceptions and intentions ranged from -7 to +7. Results of the predictive value of the HBM in this study are presented in Table 6.

Pearson product-movement correlations were used to examine the relationships between demographic data for the relative, the Health Belief Model, (scores -7 to +7) and screening behaviors. Age and education were entered as continuous variables. Income was entered as the grouped variable shown in Table 1 (page 28), while marital status was dichotomized as 'married' or 'not married'. 'Behaviors' is a computed variable which adds 1 for every reported screening behavior (BSE, CBE, and mammography); scores ranged from 0-3. Results of the correlation are displayed in Table 7.

Table 4. Reported behavior changes after intervention, 1990 study of breast cancer education for first-degree relatives.

Behavior	Number (100)
BSE	
More Careful	6
More Often/regular	8
Started Doing	3
More Aware	5
New Technique	4
Total	26
Clinical Exam (CBE)	
More Often/regular	5
Started Program	5
More Aware	2
Shared Information	1
Total	13
Mammogram	
More Often/regular	4
Started Program	5
More Aware	4
Asked Physician	3
Total	17

Table 5. Knowledge and awareness scores for experimental and control groups, 1990 study of breast cancer education for first-degree relatives.

	Group					
	Experimental		Control			
Score	Mean	SD	Mean	SD	t-value	p
Knowledge	1.34	.709	1.08	.794	2.31	.022*
Awareness	3.74	.950	3.74	1.055	.00	.997

* Significant at the $p \leq .05$ level

Table 6. Health Belief Model and screening behaviors, 1990 study of breast cancer education for first-degree relatives.

	Group					
	Screened		Not Screened			
Behavior	Mean	SD	Mean	SD	t-value	p
BSE	2.82	2.92	3.38	2.25	-1.24	.221
CBE	2.22	2.46	4.15	2.05	-5.87	.000*
Mammogram	2.83	2.58	3.93	2.03	-3.24	.001*

* Significant at the $p \leq .05$ level

Table 7. Correlations of demographics and HBM with screening behaviors, 1990 study of breast cancer education for first-degree relatives.

Variables	Age	Marital Status	Income	Education	Behaviors	HBM
Age	1.000	-.193*	-.257**	-.332**	.050	-.354
Mar Stat		1.000	-.453**	.031	.168	.199*
Income			1.000	.371**	.186*	.263**
Education				1.000	-.033	.124
Behaviors					1.000	.338**
HBM						1.000

* Significant at $p \leq .01$ level

** Significant at $p \leq .001$ level

The analysis revealed that there were low but significant correlations between demographic variables and the HBM. Age was negatively correlated with income, education, and the HBM. Marital status was negatively correlated with income. Income was positively correlated with education, behavior and the HBM, and the HBM was positively correlated with behaviors. The most likely predictor of breast cancer screening behaviors was the HBM, with income being the second.

Based on the results of the analysis, women in the experimental group were significantly more likely to practice BSE than women in the control group. Experimental group women were also more knowledgeable about breast cancer. In addition, a significant correlation was demonstrated between the Health Belief Model for clinical breast exam and mammography, but not for breast self-exam.

CHAPTER V

SUMMARY, FINDINGS, DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

This chapter presents the summary of the study, conclusions, discussion of the results, and recommendations for further study.

Summary

This study tested the effects of an educational program for first-degree relatives of breast cancer patients. It utilized a posttest only research design which allowed for random assignment of relatives to either experimental group or control group without the possible biases which might have been introduced with a pretest. The educational intervention consisted of a program where specific attention was directed to increased risk for breast cancer of first-degree relatives of breast cancer patients. The program included a packet of printed, mailed materials and a phone call from a nurse, both of which encouraged screening. There were two hypotheses which were tested in the study. Differences were considered significant if they reached or exceeded $p \leq .05$.

H_1: There would be significant differences between the experimental group and the control group with participation in breast self-exam (BSE), clinical breast exam (CBE) or mammography activities.

H_2: There would be significant differences between the experimental group and the control group in awareness and knowledge of breast cancer screening.

Patients were recruited when they came for breast cancer treatment in either the Radiation Therapy unit or the Hematology/Oncology Clinic of the Bowman Gray School of Medicine of Wake Forest University. The patients provided personal information which allowed contact with a first-degree relative (either a sister, daughter, or mother) for participation in the project. All contact with the relatives was via telephone or mail. Posttest interviews were conducted approximately three months after the nurse's phone call (experimental group) or approximately three months after interviewing the patient (control group).

Findings

Analysis of the data produced the following tests of the hypotheses:

1. There were statistically significant differences between the women in the experimental group and the women in the control group with regard to breast self-exam, but not with regard to clinical breast exam or mammography. Therefore, the first hypothesis is partially supported.
2. There were statistically significant differences between the women in the experimental group and the women in the control group with regard to knowledge, but not in regard to awareness of breast cancer and screening. Therefore, the second hypothesis is partially supported.

Discussion

Breast cancer is a leading cause of morbidity and mortality among American women and there is evidence in the literature which supports the efficacy of early detection and treatment. In addition, there are specific risk factors which have been

identified, one of the strongest being a positive family history of the disease. This program was designed to educate and encourage these high risk women to participate in breast cancer screening.

General demographic data on women at risk for breast cancer indicate that risks increase with age and higher socioeconomic and educational levels. Demographic data on both the patients and the relatives in this study reveal the population to consist primarily of white, middle-class, well-educated women who tend to be married. In addition, most of the patients were diagnosed either during or after menopause or post-hysterectomy. Mean years of survival since diagnosis are 4.7. This study population is consistent with what could be expected based on the literature.

Published information reveals that most breast lumps are found by the woman herself but evidence is lacking of whether or not the woman was doing breast self-exam (BSE) at the time she found the lump. Patients in this study revealed that most of them found the lumps themselves, consistent with the findings in the literature. Further investigation revealed that about the same numbers found the cancers while doing BSE or by accident. Nearly 19% (18.9%) discovered their breast lumps as a result of another symptom, such as pain in the breast, which prompted them to examine their breasts.

While the majority of the relatives (70.5%) in this study were practicing breast self-exam (BSE), 46% of the study participants did not have clinical breast exams (CBE) as recommended by the American Cancer Society. Even more alarming for

this high risk group, 61.5% did not get mammograms as often as was recommended by the ACS.

The theoretical basis for this study was the Health Belief Model (HBM). The findings in this study are consistent with the predictive value of the HBM. According to the HBM, the likelihood of participation in screening is a function of perceived susceptibility to a specific disease, perceived seriousness of the disease, perceived ability to participate in screening, and perceived barriers to and benefits from screening. The present study found that clinical breast exam (CBE) and mammography were predicted by the HBM, but breast self-exam (BSE) was not. These findings suggest that the HBM may be a better predictor of specific health behaviors which are practiced on an occasional basis (CBE and mammograms), than behaviors that need to be practiced on a continuous basis (BSE).

Finally, correlations between the demographics, the HBM, and the total number of screening behaviors were examined. Although there were statistically significant findings, the absolute values of many significant correlations fell between .19 and .45. Not surprisingly, age was negatively correlated with income and education. In addition, younger women were more likely to express beliefs consistent with the HBM. Being married was negatively correlated with income, but income was positively correlated with education, participation in screening, and the HBM. The HBM was most likely correlated with participation in breast cancer screening, with income being second. Certainly the correlations of income with education, the Health Belief Model, and participation in screening were consistent with what might be

predicted. It was somewhat surprising to find that education had a weak negative correlation with behaviors and a weak positive correlation with the HBM.

One concern of the researcher is that many women were not being screened with clinical breast exams or mammograms as often as is recommended and that this program did not alter that fact. One possible explanation is the short time frame of the project. While it was possible that the three-month time period may not have allowed enough time to take into account the "sleeper effect" whereby a process of attitude change must take place between the intervention and the desired action, it was assumed that if the women were going to participate in screening as a result of the intervention, they would do so within the first three months. A second three-month follow-up study with a random sample of 45 would determine if the proportion of women screened would increase (power = .80, alpha =.05, expected change = 20 percentage points) (Cohen, 1969). In addition, while few women listed actual barriers to screening when asked direct questions, many indicated that they were following their physicians' recommendations which were different from those of the American Cancer Society. A third explanation which cannot be ignored is that the phone calls revealed that these women were very busy. Some expressed the feeling that they just did not have time to be screened. Many of the relatives have small children, or sick relatives, for whom they provide some care or work two jobs, or attend both school and work.

Conclusions

This educational program in breast cancer screening was effective in increasing knowledge about breast cancer and breast cancer screening. Women in the experimental group also reported greater participation in breast self-exam.

Information concerning how the patients discovered their breast lumps emphasizes the need for continuing efforts in breast self-exam education, particularly in light of the fact that women in this study were not participating in either clinical breast exam or mammography as recommended.

The efficacy of the Health Belief Model (HBM) as a theoretical basis for educational programs in breast cancer education was demonstrated. The correlation of the HBM with screening behaviors is encouraging for future studies.

This researcher has no explanation for the negative correlation of educational level and screening behaviors. It is possible to speculate, but more practical to address the issue in a larger, follow-up study. The positive correlation of income with screening behaviors was expected since there are costs associated with both clinical breast exam and mammography. Women with lower incomes may feel they cannot afford to pay for screening, even with sliding payment scales available in the public health departments.

A major concern of the researcher is the fact that these women often reported contacting their physicians concerning screening and were told that they did not need to be screened. While most of the literature suggests that mammograms not be done on women younger than 30 years of age, many of the women who reported asking for

mammograms and being refused by their physicians were greater than 40 years of age. Clearly, physician behavior concerning high risk women needs to be addressed.

Recommendations

The program was successful in that it resulted in higher rates of breast self-exam and knowledge among the experimental group women. There are, however, several points which should be considered in future programs.

1. Telephone calls from the nurse were greatly appreciated by the participants in the study. Many expressed the same sentiment, "It's so nice to know that someone cares about us and how we feel." Surprisingly, the women expressed appreciation to both the research assistant and the principal investigator for the posttest interview phone calls!
2. The time frame of future studies should be lengthened to allow for those participants who need more time between receiving the message and taking action. It is suggested that one year might be an appropriate length.
3. Future studies should include patients who receive care from community-based oncologists and radiologists in order to reach patients who do not seek care in a tertiary care facility. This change would probably result in more minorities being enrolled in the study.
4. Programs in breast cancer screening should include evaluation of primary physicians' practices for high-risk women. It is counter-productive to encourage women to seek screening if their primary care physicians discourage it.

5. Physicians and the ACS should reach reasonable agreements on recommendations for breast cancer screening in order for programs to match recommendations and practice.

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APPENDIX A

QUESTIONNAIRE FOR PATIENT

CONSENT FORM

I understand that I am being asked to participate in a research project conducted by a faculty member of the Bowman Gray School of Medicine, who is also a doctoral student in the School of Education at the University of North Carolina at Greensboro. The study is concerned with breast cancer screening practices of close female relatives of breast cancer patients.

I understand that I will be asked questions about my background and my breast cancer. In addition, I will be asked to supply the name of one adult, female relative (mother, sister, or daughter) who may be contacted as part of this study. My interview should take about five minutes.

I understand that neither my name, nor the name of my relative, will ever be linked with the recorded responses of this interview. All responses will be completely anonymous. I may refuse to be interviewed, and if I decide to participate, I may withdraw at any time with no penalty, or loss of benefits of any kind. I further understand that supplying the name of a relative in no manner obligates her to participate in this study.

If I have further questions about this project, I may call Penny C. Sharp (919) 748-2129 at the Bowman Gray School of Medicine. If I have any questions about the rights of a research subject, I may call the Chairman of the Clinical Research Practices Committee at Bowman Gray (919) 748-2328.

All of my questions about the project have been satisfactorily answered and I agree to participate.

_____ _____

Witness Participant

_____ (____)_____

Date Participant's Phone No.

Appendix A

Questionnaire for Patient

I.D. _____

RELATIVE NAME:_____

ADDRESS:_____

CITY:_____

STATE:_____ ZIP:_____

PHONE: (___) _____

RELATIONSHIP:_____

BEST TIME OF DAY TO CALL: _____

How old were you on your last birthday?_____

What year were you diagnosed with breast cancer?_____

What is your marital status?

___ Married ___ Single ___ Divorced ___ Widowed ___ Other

What is your race? ____ Black ___ White ___ Other

What was the last grade of school you completed?_____

What was your immediate family's income last year?

a. $14,999 or below ____

b. $15,000 - 24,999 ____

c. $25,000 - 34,999 ____

d. $35,000 or above ____

Was your breast cancer diagnosed before, during or after menopause, or post-hysterectomy?_____

How was your breast cancer discovered? _____

If you found the lump yourself, was it by accident of during breast self- examination? _____

Have you discussed your breast cancer with the relative you named? _____

Do you think your relative participates in breast self-examination? ____

Do you think your relative goes to the doctor for clinical breast examinations?_____

Do you think your relative has mammography breast examinations on a regular basis?_____

Does anyone else in your family have breast cancer? _____

If so, who?

Sister/s	yes/no
Daughter/s	yes/no
Mother	yes/no
Aunt/s	yes/no
Niece/s	yes/no
Cousin/s	yes/no
Grandmother/s	yes/no

APPENDIX B

EXPERIMENTAL GROUP QUESTIONNAIRE

CONTROL GROUP QUESTIONNAIRE

Appendix B

Experimental Group Questionnaire

I.D.____

Date:_____

Hello, this is _____ and I am a research assistant at the Bowman Gray School of Medicine. I would like to ask you a few questions which should take about 20 minutes of your time. As you may recall, you received a packet of materials from us about breast cancer and Karen Masten, a nurse at Bowman Gray called you in order to answer any questions you had about the materials or breast cancer. My call is the last part of the project concerning relatives of breast cancer patients. Did you receive the packet of materials and the phone call from Ms. Masten?

Would you mind taking about 20 minutes of your time to answer some questions about breast cancer and your health practices? I would like to assure you that your answers will all be anonymous and neither your name, nor your relative's name will ever be linked to the results of this study. You do not have to participate and if you refuse, it will have no effect on your relative's treatment at Bowman Gray.

(If refuses, reason:_____)

First I would like to ask you some questions about breast self-examination.

1. Have you done breast self-examination in the last 3 months? Yes/No

When did you do the last one?_____(month)

2. Have you attended a class to learn BSE in the last 3 months? Yes/No
3. How interested are you in attending a class in BSE? (1-5 scale) _____

   1 = Not at all

   2 = Slightly interested

   3 = Uncertain

   4 = Interested

   5 = Very interested
4. Do you think you can perform BSE correctly? Yes/No
5. Have you done anything differently about BSE as a result of the packet of information you received from us or the nurse's phone call? Yes/No

   If yes, what?_____

   If not, why?_____

Next, I would like to ask you some questions about clinical breast examination.

6. Have you had a physician or other health professional examine your breasts in the last 3 months? Yes/No

   If Yes, when?_____

(If yes, skip to 10)

7. Have you ever had a physician examine your breasts? Yes/No

   How long ago?_____

   If never, why? Fear/Embarrassed/Don't need it/Don't know/Other

If other, what?_____

8. Have you made a future appointment for a clinical breast examination? Yes/No

   What is your appointment date?_____

9. How interested are you in having a clinical breast exam? ____

   1 = Not at all

   2 = Slightly interested

   3 = Uncertain

   4 = Interested

   5 = Very interested

10. Have you done anything differently about clinical breast examination as a result of either the packet of information or the nurse's phone call? Yes/No

    If yes, what?_____

    If not, why?_____

11. Do you think you would have any difficulty making an appointment and going to the doctor for a breast examination? Yes/No

    If yes, what?_____

Now, I would like to ask you some questions about mammography.

12. Have you had a mammogram, that is an x-ray examination of the breast tissue in the last three months? Yes/No

    If yes, when?_____

    (if yes, skip to 17)

13. Have you ever had a mammogram? Yes/No

    How long ago?_____

14. Have you made a future appointment for a mammogram? Yes/No

    What is your appointment date?_____

15. How interested are you in having a mammogram?_____

    1 = Not at all

    2 = Slightly interested

    3 = Uncertain

    4 = Interested

    5 = Very interested

16. Do you think you would have any difficulty making an appointment for a mammogram and keeping the appointment? Yes/No

    If yes, why?_____

17. Have you done anything differently about mammography as a result of either the packet of information or the nurse's phone call? Yes/No

    If yes, what?_____

    If not, why?_____

Next, I would like to ask you some general questions about breast cancer.

18. How concerned are you about breast cancer?

    1 = Not at all concerned

    2 = Slightly concerned

    3 = Uncertain

    4 = Somewhat concerned

    5 = Very concerned

19. How likely do you think it is that you might get breast cancer?

    1 = Not at all likely

    2 = Slightly

    3 = Unsure

    4 = Somewhat

    5 = Very likely

20. What percent of breast cancer do you think can be cured if it is found early and treated correctly?_____%

21. Have you ever discussed your (relative's) breast cancer with her? Yes/No

    If not, why?_____

(If no, skip to 25)

22. Did she encourage you to do BSE? Yes/No

23. Did she encourage you to have a clinical breast examination? Yes/No

24. Did she encourage you to have a mammogram? Yes/No

I need to have some information on your background.

25. How old were you on your last birthday?_____

26. What is your marital status?

____ Married

____ Single/Separated

____ Divorced

____ Widowed

____ Other

27. What was your total household income last year?

a. $14,999 or below ____

b. $15,000 - 24,999 ____

c. $25,000 - 34,999 ____

d. $35,000 or above ____

28. What was the last grade of school you completed?___

(Control Group Questionnaire)

I.D._____

Hello, my name is _____ and I am a research assistant at the Bowman Gray School of Medicine. I am calling concerning a research project designed to learn more about women and breast cancer screening practices. I would like to ask you a few questions which should take about 20 minutes of your time. As you know, your (relative), _____, has breast cancer and she gave us your name and said that we could call you concerning our project. I would like to assure you that your or your (relative's) names will never be connected with the answers which you may give me or any part of the study. We are talking to about 200 relatives of breast cancer patients.

Would you mind answering some questions which will take about 20 minutes of your time?

(If respondent refuses, record reason:

_____

First I would like to ask you some questions about breast self-examination.

1. Have you done breast self-examination in the last 3 months? Yes/No

   When did you do the last one?_____(month)

2. Have you attended a class to learn BSE in the last 3 months? Yes/No

3. How interested are you in attending a class in BSE? (1-5 scale) _____

   1 = Not at all

   2 = Slightly interested

   3 = Uncertain

   4 = Interested

   5 = Very interested

4. Do you think you can perform BSE correctly? Yes/No

Next, I would like to ask you some questions about clinical breast examination.

5. Have you had a physician or other health professional examine your breasts in the last 3 months? Yes/No

   If Yes, when?_____

(If yes, skip to 10)

6. Have you ever had a physician examine your breasts? Yes/No

   How long ago?_____

   If no, why? Fear/Embarrassed/Don't need/Don't know/Other

   If other, what?_____

7. Have you made a future appointment for a clinical breast examination? Yes/No

   What is your appointment date?_____

8. How interested are you in having a clinical breast exam? _____

   1 = Not at all

   2 = Slightly interested

   3 = Uncertain

   4 = Interested

   5 = Very interested

9. Do you think you would have any difficulty making an appointment and going to the doctor for a breast examination? Yes/No

   If yes, why? _____

Now, I would like to ask you some questions about mammography.

10. Have you had a mammogram, that is an x-ray examination of the breast tissue in the last three months? Yes/No

    If yes, when?_____

    (If yes, skip to 15)

11. Have you ever had a mammogram? Yes/No

    How long ago?_____

    If never, why? Fear/Embarrassment/Don't need/Don't know/Other

    If other, what? _____

12. Have you made a future appointment for a mammogram? Yes/No

    What is your appointment date?_____

13. How interested are you in having a mammogram?_____

    1 = Not at all

    2 = Slightly interested

    3 = Uncertain

    4 = Interested

    5 = Very interested

14. Do you think you would have any difficulty making an appointment for a mammogram and keeping the appointment? Yes/No

    If yes, why?_____

Next, I would like to ask you some general questions about breast cancer.

15. How concerned are you about breast cancer?____

    1 = Not at all concerned

    2 = Slightly concerned

    3 = Uncertain

    4 = Somewhat concerned

    5 = Very concerned

16. How likely do you think it is that you might get breast cancer?____

    1 = Not at all likely

    2 = Slightly

    3 = Unsure

    4 = Somewhat

    5 = Very likely

17. What percent of breast cancer do you think can be cured if it is found early and treated correctly?_____%

18. Have you ever discussed your (relative's) breast cancer with her? Yes/No

    If not, why?_____

(If no, skip to 22)

19. Did she encourage you to do BSE? Yes/No

20. Did she encourage you to have a clinical breast examination? Yes/No

21. Did she encourage you to have a mammogram? Yes/No

I need to have some information on your background.

22. How old were you on your last birthday?_____

23. What is your marital status?

    ____ Married

    ____ Single/Separated

    ____ Divorced

    ____ Widowed

    ____ Other

24. What was your total household income last year?

    a. $14,999 or below ____

    b. $15,000 - 24,999 ____

    c. $25,000 - 34,999 ____

    d. $35,000 or above ____

25. What was the last grade of school you completed?___

APPENDIX C

SAMPLE LETTER SENT TO EXPERIMENTAL GROUP

SAMPLE LETTER SENT TO CONTROL GROUP

BREAST CANCER BROCHURE FOR FIRST-DEGREE RELATIVES

WAKE FOREST

The Bowman Gray
School of Medicine

The Department of Family
and Community Medicine
(919) 748-4479

September 25, 1990

^OParticipant Name^O^C
^OStreet Address^O^C
^OCity, State, Zip Code^O^C

Dear ^OParticipant Name^O^C:

I am sending you the enclosed materials about breast cancer screening as part of a project designed to inform women about the value of early detection of breast cancer. Your name was given to me by your ^ORelative, Name^O^C, who is receiving treatment for breast cancer at the Bowman Gray School of Medicine of Wake Forest University.

We have learned that finding breast cancer early is very important and modern technology is making it easier and easier to do this. The three methods of screening for breast cancer are breast self-examination, clinical examination and mammography. The enclosed materials will explain more about each of these.

In addition to these materials, you will be getting a phone call from a nurse who is involved with this project, Karen Masten, R.N., M.S.N. Karen will be calling within the next week and will be ready to answer any questions which you may have about breast cancer and screening for breast cancer. Please write down any questions that you may have after reading these materials so that she can answer them for you.

If you have any additional questions about this project or about why you received this information, please feel free to call me collect at (919) 748-2129. If I am not in my office at the time of your call, I will return your call as soon as possible.

Sincerely,

Penny C. Sharp, M.Ed.
Instructor in Family & Community Medicine
^T^N^P^P

300 South Hawthorne Road, Winston-Salem, North Carolina 27103
TELEX 806449 BGSM WSL TELEFAX (919) 748-4204

WAKE FOREST

The Bowman Gray
School of Medicine

The Department of Family
and Community Medicine
(919) 748-4479

September 25, 1990

^OParticipant Name^O^C
^OStreet Address^O^C
^OCity, State, Zip Code^O^C

Dear ^OParticipant Name^O^C:

I am sending you the enclosed materials about breast cancer screening as part of the project designed to inform women about the value of early detection of breast cancer. As we told you during the telephone interview, your name was given to me by your ^ORelative, name^O^C, who is receiving treatment for breast cancer at the Bowman Gray School of Medicine of Wake Forest University.

We have learned that finding breast cancer early is very important and modern technology is making it easier and easier to do this. The three methods of screening for breast cancer are breast self-examination, clinical examination and mammography. The enclosed materials will explain more about each of these.

In addition to these materials, you will be getting a phone call from a nurse who is involved with this project, Karen Masten, R.N., M.S.N. Karen will be calling within the next three weeks and will be ready to answer any questions which you may have about breast cancer and screening for breast cancer. Please write down any questions that you may have after reading these materials so that she can answer them for you.

If you have any additional questions about this project, please feel free to call me collect at (919) 748-2129. If I am not in my office at the time of your call, I will return your call as soon as possible.

Sincerely,

Penny C. Sharp, M.Ed.
Instructor in Family & Community Medicine
^T^N^P^P

300 South Hawthorne Road, Winston-Salem, North Carolina 27103
TELEX 806449 BGSM WSL TELEFAX (919) 748-4204

Breast cancer is one of the lead-
ing causes of illness a-
among American w-
the most d-
yo-

When a Relative has Breast Cancer: What Sisters, Daughters & Mothers Need to Know.

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-e are any dif-
-ie shape or size or if
-kin looks different. He or she will then feel your breasts, chest and armpits for any lumps. You should have this exam every 1 to 2 years until you reach 35 years of age, then once every year.

That's the bad news. Now for the good! Breast cancer can be cured!

The sooner cancer of any kind is found, the better the chances are that it can be cured. This is true of breast cancer. If the breast lump is found early and treated about 9 out of every 10 breast cancers can be cured.

How can you find out if you have breast cancer? Well, there are three ways that you can check.

1. **Breast Self-examination:** An examination of all of her own breast tissue by a woman. Because the breasts are located on the outside of the ribs, you can feel the tissue to see if there are any lumps which might mean

3. **Mammogram:** An x-ray examination of the breast tissue. Women also need to have their breasts examined by x-ray. This exam, a mammogram, uses very low doses of x-ray. It is one of the safest and best ways to find very small breast lumps, while the cancer is the easiest to cure. You should have a mammogram every other year from age 35 to 40 and every year after age 40.

Early detection is the key. You hold the key.